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AUTHOR Ellis, Gail Johnston
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ABSTRACT

Epilepsy affects approximately one percent of the population, with most cases having onset during childhood. School personnel can best incorporate the child with epilepsy into the classroom and provide support for families by becoming familiar with the types of seizure disorders, the issues that epilepsy presents for children and families, and the supports that children and families need. This paper provides information on: (1) seizure types, what they look like, first aid, and what not to do; (2) common misconceptions and negative attitudes regarding epilepsy that can compromise a child's ability to participate actively in social and school activities; (3) difficulties in diagnosis and medication and resulting family stress; (4) possible scholastic difficulties; and (5) the benefits and drawbacks of rural living and rural schools for children with epilepsy and their families. Two brief case studies illustrate the social, emotional, and academic effects that epilepsy can have on children. Ways in which the school can alleviate some of the problems of students with epilepsy and their families are suggested, including an information seminar for the entire school about epilepsy and associated problems, designating one staff member to be a support person for the student, and maintaining frequent family contacts. Information sources on epilepsy for teachers and family are noted. (SV)

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RURAL ISSUES FOR CHILDREN AND FAMILIES AFFECTED BY EPILEPSY

Gail Johnston Ellis
Assistant Director
Department of Children, Youth and Families
Epilepsy Foundation of America

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Gail Johnston Ellis
Assistant Director
Department of Children, Youth and Families
Epilepsy Foundation of America

RURAL ISSUES FOR CHILDREN AND FAMILIES AFFECTED BY EPILEPSY

Introduction

Epilepsy is a chronic health problem which often begins during the school years and which presents a unique set of concerns and issues for children with seizure disorders and their families. These issues may become even more troublesome for rural families who do not have access to some of the services and supports generally available in metropolitan areas. School personnel can best incorporate the child with epilepsy into the classroom and provide support for families by becoming familiar with the types of seizure disorders, the issues which epilepsy presents for children and families, and the supports which children and families need. The efforts of school personnel to assist children with epilepsy and their families can benefit students throughout their lives.

About Epilepsy

Epilepsy affects approximately 1% of the population, with a majority of cases having onset during childhood. Approximately one child in every 100 will have a seizure by the age of 14. School administrators and educators can expect the children in their schools to have epilepsy in roughly these proportions.

Epilepsy is a chronic disorder which is characterized by recurrent seizures. A seizure is a time-limited event involving involuntary behavior which results from temporary abnormal firing of neurons in the brain. There are many different kinds of seizures, and individuals with epilepsy represent a wide spectrum of disability. Later we will look at two children who have different types of seizure disorders, and will examine how their seizures affect their functioning and inclusion in the classroom. First, we need to understand a little more about seizures.

There are two basic categories of seizures, the generalized kind, which involves a temporary loss of consciousness, and the partial kind, which involve no loss of consciousness or may cause an altered state of consciousness. Within these two categories are many specific types of seizures, from the kind which cause an individual to fall to the ground with severe jerking of the muscles, to kinds which can take place without anyone else even knowing that a seizure occurred. The Seizure Recognition and First Aid chart describes the major types of seizures, what they look like, and the proper first aid for each. It is helpful for administrators and educators to be familiar with what the different types of seizures look like so that they can identify possible seizure activity in children in their schools.

For our purposes, the most important thing to know about seizures is that anything the brain can do normally during daily activities, it can do abnormally during a seizure. This means that a seizure could involve the entire body or a single body part. A seizure can involve feelings, tastes, smells, sights, sounds, or an absence of movement. The person sitting right next to you could have a seizure without you being aware of it. Understandably, this can make seizures especially difficult to detect, since they are often confused with other medical conditions or with psychotic or substance-induced behavior. Episodes might start with one kind of seizure, and then generalize into another kind. Additionally, a person can have several kinds of seizures as part of his epilepsy, or the type of seizure may change over time.

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Seizure Recognition and First Aid

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SEIZURE TYPE	WHAT IT LOOKS LIKE	WHAT IT IS NOT	WHAT TO DO	WHAT NOT TO DO
GENERALIZED TONIC-CLONIC (Also called Grand Mal)	Sudden cry, fall, rigidity, followed by muscle jerks, shallow breathing or temporarily suspended breathing, bluish skin, possible loss of bladder or bowel control. Usually lasts a couple of minutes. Normal breathing then starts again. There may be some confusion and/or fatigue, followed by return to full consciousness.	Heart Attack. Stroke.	Look for medical identification. Protect from nearby hazards. Loosen ties or shirt collars. Protect head from injury. Turn on side to keep airway clear. Reassure when consciousness returns. If single seizure lasted less than 5 minutes, ask if hospital evaluation is wanted. If multiple seizures, or if one seizure lasted more than 5 minutes, call an ambulance. If person is pregnant, injured, or diabetic, call for aid at once.	Don't put anything hard in the mouth. Don't try to hold tongue. It can't be swallowed. Don't try to give liquids during or just after seizure. Don't use artificial respiration unless breathing is absent after muscle jerks subside, or unless water has been inhaled. Don't restrain.
GENERALIZED ABSENCE (Also called Petit Mal)	A blank stare, beginning and ending abruptly, lasting only a few seconds, most common in children. May be accompanied by rapid blinking, some chewing movements of the mouth. Child is unaware of seizure, but quickly returns to full awareness once it has stopped.	Daydreaming. Lack of attention. Deliberate ignoring of adult instructions.	No first aid is necessary, but if this is the first observation of the seizure(s), medical evaluation should be recommended.	
COMPLEX PARTIAL (Also called Temporal Lobe or Psychomotor)	Usually starts with blank stare, followed by chewing, followed by random activity. Person appears unaware of surroundings, may seem dazed, and mumble. Unresponsive. Actions clumsy, not directed. May pick at clothing, pick up objects, try to take clothes off. May run, appear afraid. May struggle or flail at restraint. Once pattern is established, same set of actions usually occurs with each seizure. Automatic behavior usually the same with each seizure. Lasts a few minutes, but post-seizure confusion can last substantially longer. No memory of what happened during seizure period.	Drunkenness. Intoxication on drugs. Mental illness. Disorderly conduct.	Speak calmly and reassuringly to patient and others. Guide gently away from obvious hazards. Stay with person until completely aware of environment. Offer to help getting home.	Don't grab hold unless sudden danger (such as a cliff edge or an approaching car) threatens. Don't try to restrain. Don't shout. Don't expect verbal instructions to be obeyed.
SIMPLE PARTIAL	Jerking may begin in one area of body, arm, leg, or face. Can't be stopped, but patient stays awake and aware. Jerking may proceed from one area of the body to another, and sometimes spreads to become a convulsive seizure. Partial sensory seizures may not be obvious to an onlooker. Patient experiences a distorted environment. May see or hear things that aren't there, may feel unexplained fear, sadness, anger, or joy. May have nausea, experience odd smells, and have a generally "funny" feeling in the stomach.	Acting out, bizarre behavior. Hysteria. Mental illness. Psychosomatic illness. Para-psychological experience.	No first aid necessary unless seizure becomes convulsive, then first aid as with Complex Partial. No immediate action needed other than reassurance and emotional support. Medical evaluation should be recommended.	
ATONIC SEIZURES (Also called Drop Attacks)	A child or adult suddenly collapses and falls. After 10 seconds to a minute he recovers, regains consciousness, and can stand and walk again.	Clumsiness. Normal childhood "stage" in a child, lack of good walking skills. In an adult, drunkenness, acute illness.	No first aid needed unless he hurt himself as he fell, but the child should be given a thorough medical evaluation.	
MYOCLONIC SEIZURES	Sudden brief, massive muscle jerks that may involve the whole body or parts of the body. May cause person to spill what they were holding or fall off a chair.	Clumsiness. Poor coordination.	No first aid needed, but should be given a thorough medical evaluation.	
INFANTILE SPASMS	These are clusters of quick, sudden movements that start between 3 months and 2 years. If a child is sitting up, the head will fall forward, and the arms will flex forward. If lying down, the knees will be drawn up, with arms and head flexed forward as if the baby is reaching for support.	Normal movements of the baby. Colic.	No first aid, but doctors should be consulted.	

The Effect of Epilepsy on Children

After this quick review of the variety of ways seizures can manifest themselves, it is understandable that epilepsy can have a very serious impact on children with seizure disorders and their families. Let's consider first the unique nature and social consequences of epilepsy.

Seizures are events which are uncontrollable, unpredictable, and adversive. They are caused by electrical events in the brain which the individual cannot predict or control. Individuals with seizures and those around them have little ability to make adaptations to the environment. Moreover, due to the social history and negative beliefs held about epilepsy, important life events including social relationships, integration with peers, and employment may become compromised. The effects of seizures themselves are physical, emotional, psychological, behavioral, and cognitive. Seizures can affect an individual's ability to function in every area of life activity.

The following misconceptions about epilepsy are still common today:

- **Individuals with epilepsy are mentally retarded**. Actually, intelligence among individuals with epilepsy does not differ significantly from intelligence among the general population. Although seizures or medication side effects may interfere with learning, IQ among individuals with epilepsy follows the same bell-shaped curve as among other individuals.

- **Individuals with epilepsy are mentally ill**. There is no relationship between epilepsy and mental illness. Epilepsy and mental illness are separate conditions. Some types of seizures may involve phenomenon which seem like mental illness (seeing things, hearing things) but they are not related to mental illness in any way.

- **Epilepsy is contagious**. Epilepsy is a symptom of brain dysfunction and cannot be passed from one person to another as a contagious illness can be.

- **Individuals with epilepsy should be placed in separate learning and living situations to provide the special care that they need**. Most individuals with epilepsy have well controlled seizures and live normal lives. They are able to go to school with their peers, work with their peers, and make contributions to the community. Even those individuals whose seizures are poorly controlled do better, achieve more, and have a better quality of life when integrated with their peers than when segregated. There is no reason to separate a person with epilepsy from his or her peers.

- **People with epilepsy should not participate in sports or other vigorous activities**. In most cases, individuals with epilepsy can participate in just about every activity that individuals without epilepsy enjoy. Some activities might need to be adapted to make them safer in the event of a seizure, but almost all activities can be participated in at some level.

These misconceptions can have a profound impact on an individual with epilepsy, creating negative beliefs and opinions which compromise the individual's ability to participate actively in social and school activities.

Another aspect of epilepsy which significantly affects individuals with seizure disorders is its hidden nature. You can't tell by looking at someone that they have epilepsy. While it may seem that this would be a benefit, a major drawback is that it is difficult to receive social support when others cannot tell that you are in need of it. No one else knows that constantly, in the back of your mind, is the knowledge that a seizure could happen at any time. One nine year old girl described it as feeling like you're walking around with a bomb in your head which could explode at any moment.

Another issue is the loss of personal control which seizures involve. One minute the individual is functioning in their usual, goal-directed way and then, for no reason at all, the next minute they lose control. Since others make judgments about us based upon our ability to behave within certain parameters, this inability to count on an individual with epilepsy to always behave within these parameters, compounded by the fact that seizures manifest themselves in an infinite variety of ways, makes epilepsy frightening.

Now that we have a basic understanding of the unique nature of epilepsy, some of the misconceptions that face individuals with seizure disorders, and social consequences of seizures themselves, let's look at what happens to the child and the family when a child has epilepsy. First, depending on the type of seizure that the child has, epilepsy may be the furthest thing from the family's mind when they begin to notice a problem. Consider the types of seizures described on the chart: some are characterized by a blank stare ("He's daydreaming again!"), some are characterized by simple movements of one body part ("He has this twitch in his thumb every now and then."), some involve more complex movements of the individual ("He's hyperactive -- sometimes he just walks around in circles."), and some involve the senses ("He's having hallucinations." or "He gets these sudden stomach aches."). Depending on the initial complaint, the family and the family doctor will pursue treatment which seems appropriate for the problem. The difficulty in diagnosing many types of seizures often involves a lengthy, frustrating process in which parents or even the child himself may be disbelieved, accused of wrong-doing, or assumed to have psychological or behavioral problems. Through EFA's Parent and Family Network and national toll-free information and referral line, we have heard repeated stories of families starting with a doubtful family doctor, then going from one specialist to another, with children undergoing series after series of tests and hospitalizations for years at a time before a diagnosis is finally made. Currently, there is no one definitive medical test for epilepsy. Diagnosis is primarily based upon descriptions or observations of symptoms, and the clinical history of the child. This process in itself creates a tremendous amount of stress for the child and the family.

Once a diagnosis of epilepsy has finally been made, the difficulties for children and families don't end. There is often a lengthy process of trying different medications and dosage levels before the most effective combination can be achieved, during which time seizure activity continues at various levels and with various medication side effects. The repeated rising of the family's hopes as a new medication is tried, the pain and anxiety of dealing with side effects, the eventual disappointment and the need to try something else, creates an emotional roller-coaster for the child and family alike. Add to this the fact that changes in the child's body chemistry, which are a normal part of growth and development, wreak havoc with medication and can repeatedly throw a family back into the process of trying to find the right medication and the right dosage.

Earlier we discussed the inability to know when a seizure may occur, and the difficulty which this causes for individuals with epilepsy. In children, this creates a constant anxiety because of their concern for what may happen during a seizure and how their peers will react. Children and parents have frequently expressed that the fear of a seizure occurring is often more debilitating than the occurrence of a seizure itself. Even when children have achieved good control of seizure activity, the fear that a seizure could break through at any time is always present. Parents, extended family members, and others in the child's environment tend to be very protective of a child with a history of epilepsy, curtailing normal activities for fear of a seizure. The constant state of worry and fear is taxing on everyone, and can interfere with daily activities and relationships with others.

As we discussed earlier, misconceptions about epilepsy can be extremely damaging. Stories that other children have heard can make it very difficult for the child

to make friends. Children may taunt the child with epilepsy, gossip quietly among themselves, or simply shun the affected child. Some seizures involve behavior which can be embarrassing and which other children may perceive as bizarre. Other children may wonder at the child with epilepsy's inability to control his or her own behavior.

Finally, scholastic difficulties ranging from very minor memory problems to severely impaired scholastic functioning are common among children with epilepsy. Although most children have relatively uncomplicated epilepsy, with good seizure control and minimal or no side effects, there are those children whose epilepsy interferes with daily functioning. At the very least, a child who has several seizures a week or a day has many interruptions in the learning process. Children may have to come to school late or miss a day of school due to a seizure. Even very brief but frequent staring spells interrupt the flow of information to a child and may cause learning difficulties.

Even those children whose seizures are well controlled by medication may have scholastic difficulties. Although current research is not definitive about how they are related, we know that children with seizure disorders are somewhat more inclined to have learning differences than those without epilepsy. It may be that the underlying cause of the seizures is responsible for the learning differences, which may include short-term memory loss and difficulties processing information. While their abilities in terms of intelligence are generally average, these students may need to have information repeated to them or may require presentation of material in alternative ways. Additionally, children may find it hard to concentrate on work because of their concern for how they are perceived by their peers, or due to the fear that a seizure might occur at any moment. Side effects of medication, which may include drowsiness, poor coordination, irritability, mood swings, lethargy and hostility, can make it difficult for the child to concentrate on school work. Additionally, the child's ability to concentrate may vary throughout the day as the medication reaches different levels in the child's bloodstream.

Case Studies

Although most children with epilepsy do not have other disabilities, it's important to recognize that epilepsy does occur in association with other disabilities. Epilepsy occurs in 30% of children with cerebral palsy; 9-32% of children with mental retardation; 50% of children who have both cerebral palsy and mental retardation; and 11-35% of children with autism. This means than children in special education classes or children with a primary diagnosis other than epilepsy may also have seizure disorders which are affecting their ability to function in the classroom and their social interactions.

Even those children without other disabilities can be compromised to some degree by their epilepsy. To better understand the wide spectrum of difficulties which children with epilepsy may have, and to see how the various issues may interact, let's look at a couple of children and their seizure disorders. Neither of the children described below have a diagnosis of other disabilities in addition to epilepsy.

Michele is thirteen years old. She has several different kinds of seizures. One of the kinds of seizures she has makes her suddenly fall to the ground, which means that she has to wear a helmet. Michele has an IQ of 90 but has difficulty learning because her concentration and attention is affected by daily absence seizures. Michele is able to walk without assistance but her gait is clearly affected by the antiepileptic medication she must take. Michele attends all special education classes at her public school and her only peer interaction is with other individuals with disabilities. Michele is argumentative, seldom smiles, and has generally poor social skills. She hates

her helmet because she can't style her hair, wants to wear make-up, fears that she will never have a boyfriend, and believes that every time she walks through the hall at school the other kids are talking about her. Michele's parents have suggested that she might respond well to participating in some classes with students without disabilities, but the school principal feels that Michele is safer and that they are better able to deal with the possibility of a seizure in the special education classroom. Besides, with her poor social skills she would be likely to ostracize herself even more if she were in classes with other students.

Paul is a seven year old boy. Since the age of five he has had seizures during which he typically becomes very emotional, crying and alternately clinging to and pushing away from whoever is near him. Paul may get up and walk, seems unaware of his surroundings, and cannot respond to other people during the seizure. He is currently taking two kinds of medications which make him drowsy but which do not control the seizures well. Paul seems to have difficulty reading for extended periods of time, complains of headaches, double vision, and twitches in his eyes. He feels that he learns more easily when his mother reads his textbooks aloud and discusses the material with him. Although of average intelligence, Paul is doing poorly in school. He is in a regular education classroom and has no friends in the class. Paul's teacher is aware of his seizures, but has not shared the diagnosis with the other children at the request of Paul's parents. If you ask the other children about Paul, they are likely to say that he is "crazy."

These cases illustrate just a few of the various effects which epilepsy can have on a child. In spite of the myriad issues which can affect children with epilepsy, most children with seizure disorders adapt well and have the ability to do at least satisfactory work in school. The difficulties which the children described above experience can be partially alleviated by school personnel who work with the child and family to find solutions to the issues.

We will revisit Michele and Paul a little later.

Rural Living and Epilepsy

Rural living presents opportunities for a wide range of experiences and support, for all children, which are often not as readily available in urban or suburban environments. Likewise, there can be drawbacks to living in a rural area with reduced access to some of the services available in more metropolitan areas. Let's take a moment to look at the benefits of rural living for children for children with epilepsy, along with some of the drawbacks.

One of the unique characteristics of rural living is the close-knit community which generally develops in spite of tremendous distances separating families from one another. Unlike in busy metropolitan areas, where one can live for years in an apartment and never meet the person living on the opposite side of the wall, rural families are likely to call anyone living within a ten mile radius "neighbor." Popping into each other's homes while passing by is far more common in rural than in metropolitan areas, as are informal gatherings for the purposes of socializing and enjoying one another's company. Families tend to know each other better and pitch in to help each other more in rural communities than in urban ones. The extended network of family and friends throughout the area provides a richness of experience and opportunities to support one another that is often lacking in the big city, and which can be especially beneficial to families affected by epilepsy.

Another characteristic of rural communities is the focus of attention on two primary systems, the church and the school. Unlike in urban areas where there is often a profusion of community centers, social service organizations, clubs, and gathering places, activities in rural areas often are initiated through one of these two systems. This provides clergy and school personnel with a unique ability to

offer support, information, and opportunities for learning. Likewise, clergy and school personnel play a greater variety of roles in the lives of individuals and families than they would likely play in an urban area. They may be approached not only with matters of religion and learning, but with marital difficulties, financial concerns, requests to settle an argument with a neighbor, and a whole host of presenting problems. The tremendous opportunity to help and support individuals and families is accompanied by a great deal of responsibility.

The school system combines both of these factors to provide a cohesive learning environment which is at once structured and supportive. Rural schools generally have a smaller number of teachers who know each other well and provide support and information to each other. Teachers, counselors and administrators work well together as a team and share information about students and how they feel they can best support them. Children are individuals who are known by all school personnel, from the cafeteria workers to the school administrator. This team approach to working with a child can be especially beneficial to a child with a disability or a chronic illess such as epilepsy. The rural school is able to play a unique role, providing support, encouragement, and direction.

These characteristics of rural living and in particular, rural schools, can be extremely beneficial to the child with epilepsy. Unfortunately, there are also drawbacks to rural living which may compound some of the difficulties of children with epilepsy and their families. Let's take a moment to look at how living in a rural area might make some of those issues even more difficult to address.

The first issue which we discussed was the unique nature of epilepsy and the social consequences of the disorder. The key to alleviating some of the social consequences is information. Both of the children discussed in the previous case studies could have improvement in school life and performance if their peers and educators had factual information about epilepsy and its effects. Unfortunately, rural living makes it more difficult to access resources which could provide this information. Human service or health organizations which have a specialization in understanding seizure disorders may be hundreds of miles away. Local doctors or other health professionals often have only very limited time for presentations to schools, and most likely will have only received a very small amount of information about epilepsy during their training. Finding an individual with current information about the wide variety of seizures and the broad spectrum of associated disability, who is able to present the material in the appropriate manner, can be difficult even in a metropolitan area with vast resources. This difficulty is much greater in rural areas.

Associated with the need for information is the need for support from others affected by epilepsy. Although the wonderful network of friends and family in rural areas can provide tremendous support, families tell us that they want to talk to other parents whose children have epilepsy, preferably parents whose child is around the same age and has the same type of seizures or associated disabilities. They may feel embarrassed about the condition or believe that others would not understand, resulting in a reluctance to reach out to others in their community. Talking with other parents and learning how they coped with the diagnosis helps families to feel empowered to deal with the condition and lets them know that they are not alone. Children need contact with other children who have epilepsy, to discuss their feelings and their hopes. In rural areas, finding other families affected by epilepsy can be next to impossible.

The second problem which was discussed was that of diagnosis. The difficulty in finding a doctor who will listen seriously to the family's description of the problem, the need to visit numerous sites to undergo medical tests, and the process of finding appropriate medical care once a diagnosis is made are all extremely frustrating in a large city with state-of-the-art facilities. In rural areas a general practitioner with little

training in seizure disorders may be the only doctor available. Again, depending on the type of symptom being described, the doctor may recommend a psychologist, psychiatrist, cardiologist, urologist, or an optometrist. The family might be referred to specialists who are far from their homes, and still may not be seeing the right kind of specialist. Traveling to various cities means the child misses school, the parent(s) miss time from work, care for other children has to be arranged, and the entire family is exhausted. Eventually, the family may find its way to a pediatric neurologist four hours away who finally diagnoses epilepsy. Even then, this doctor may not be someone with whom the family feels comfortable or who cannot provide the quality of medical care the family would like. Finding a physician who listens, who seems knowledgeable about the specific seizure type of the child, and with whom the family feels a partner in medical care is very important, and may take quite some time after initial diagnosis is made.

All of these problems are associated with distance, and are difficult to overcome for the rural family with significant resources in terms of education, finances, job stability, communication abilities, and transportation. Let's take a moment to consider this in association with what we know to be common characteristics of rural families. First and foremost, we know that rural families have less of a tendency to be in contact with organizations or groups outside of their own community, and therefore lack some of the information available through those channels. Rural areas may have their own culture and social system. The church, which plays such an important role in supporting rural families, may be turned to instead of seeking medical care. Especially for families who have not received much information about epilepsy, the individual displaying "different" behavior might be brought to the church community for prayers because the problem does not appear to be a medical one. Cultural beliefs may also encourage families to keep the individual who is "different" at home and to deal with the problem through the extended system of family and friends, thus making it less likely that medical treatment and support from others affected by epilepsy would be provided. Language barriers might also be present. The inability to communicate comfortably with doctors and human service providers may make these families less likely to seek assistance for a problem as inexplicable as seizures seem.

Finally, finances represent a serious obstacle for the rural family in need of specialized medical services. Let's go back to the stage of diagnosis. We discussed how families generally move from doctor to doctor, specialist to specialist before finally getting a diagnosis of epilepsy. The cost of traveling, staying in hotels while tests are run, and providing for the needs of other children during the trip are exorbitant. Middle-income and affluent families find that these necessary visits take a large bite out of savings or other resources. For the rural family with a low income, these costs may make the trips impossible. This is assuming that the family has insurance coverage. The cost of the medical care alone, even if it were in the vicinity, would be prohibitive to a family without health insurance. Assuming that the family is able to find transportation and the money needed to make the trips to obtain a diagnosis, they may not be able to afford ongoing care or quality care after the diagnosis is made. Changes in seizure type or severity may go without further treatment, and the family may not be able to take advantage of new medications or medical breakthroughs which might offer new hope for the disorder. In any case, the rural family may be devastated by the medical bills and cost of travel.

Each of these potential issues of rural families, taken alone, can make it extremely difficult for the family to adjust to the disorder and for the child to achieve his or her potential in school. Taken together, these difficulties can lead to a range of problems, from family dysfunction to severe depression or behavioral problems in the child with epilepsy. Take just a moment to consider how a child with epilepsy must feel when he sees his entire family turned upside down emotionally, financially, and structurally by his disorder; when his classmates and sometimes school personnel respond

negatively to his problems associated with the seizure disorder; and when he is unable to exercise control over himself or his environment. Appropriate support for the child and the family can make a tremendous amount of difference for everyone involved.

What Can We Do?

We've spent quite a bit of time becoming familiar with the types of seizure disorders, the associated disabilities, the effects which epilepsy can have on the child and the family, and the way rural living may help or compound some of those effects. Understanding epilepsy is the first step in providing the support which the child and the family needs. The school system cannot possibly be expected to alleviate all of the problems of the rural family coping with epilepsy. Because of their unique position in the community and in the life of the child, however, school administrators and educators can provide the support and assistance the child with epilepsy needs to achieve scholastically and socially, while helping the family to adapt to the disorder by providing support during regular interactions with family members.

Let's go back to the youngsters with epilepsy discussed earlier. Michele may be correct in thinking that the other children are looking at her "funny" when she walks down the hall. An information seminar provided to the entire school about epilepsy and associated problems would be a good starting point. It seems that for Michele, integration with her peers is a critical step. Her parents had already tentatively broached this subject, but understood the school administrator's concern for Michele's well-being and desire to keep her in a protected environment. This is actually an excellent opportunity for the school administrator to take a strong stand on integration of children with epilepsy and other disabilities. Michele's segregation is clearly not benefitting her, as she is doing less well scholastically and socially than we would expect of a child with her capabilities. Michele has few seizures, and wears headgear to protect her in the event of a seizure. The potential risk of harm to Michele seems small in comparison to the benefits. Prior to and during her transition into some regular education classes, it would be important for Michele to have a member of the school staff spend time alone with her talking about how she feels about her disorder and working on socialization skills. Extensive knowledge of epilepsy is not necessary for someone to be the compassionate, listening ear which Michele needs. Michele's parent(s) might be asked if the neurologist has considered reducing her medication or considering whether she still needs to wear the helmet. Naturally, this discussion would have to be carefully handled in order to not compromise the school's relationship with the family or the family's relationship with the neurologist. Helping Michele to feel as "normal" as possible could be the key to helping her reach her potential.

The case of Paul is somewhat different. Paul is already integrated with his peers. He looks like everyone else except when he has a seizure. Again, providing information is an important first step to helping the other children to understand what is going on with Paul. School personnel would need to meet with Paul's family and explain what they have observed. Expressing an understanding of what the family may be experiencing may help to gain their permission to discuss Paul's epilepsy with the class. The Epilepsy Foundation of America has several excellent videos for young children about epilepsy which could help to explain the condition to Paul's classmates and school personnel. By helping Paul and his classmates to interact positively regarding his seizures, he can be better integrated into the classroom. Paul's parents may also want to consult with their physician about the effects of the medication on his school work. The dosage might be able to be reduced or perhaps the times when it is taken changed so that the effect during school isn't as great. The clue that Paul has given about his discomfort when reading might be a signal to Paul's teachers or administrator that he has difficulty processing information which he reads,

and an alternative system can be set up for him to gain information. By involving Paul's parents and doctor, teachers and administrators can help to overcome some of the obstacles to Paul's success.

In both of these cases, the understanding of the educator and administrators of what the child and the family are going through are paramount to providing support and assistance. The knowledge that the family may be faced with overwhelming emotional, financial, and logistical problems can help the school staff to be understanding and supportive of issues which arise such as the child missing school, the family not being able to participate in bake-sales or other school activities, or even the family's reluctance to talk about the child's epilepsy. Each family is at a different place in dealing with the disorder, and should be approached with a willingness to listen and help without pushing the family to take steps before they are ready. Sending encouraging notes home, offering any materials about epilepsy or seizures which might be available, and providing resources that might be helpful can go a long way to helping families feel less isolated and more willing to reach out for support.

Another important aspect of the intervention planned by the team of school personnel is the effort to make the child with epilepsy and the epilepsy itself an accepted part of life for everyone in the school. Complete integration of children with epilepsy is critical to alleviating some of the stigma and "differentness" these children feel. Providing epilepsy education programs to the students and staff helps them to understand epilepsy as just another aspect of the student which should not interfere with their inclusion, like having brown hair or blue eyes. For the child with epilepsy, having the seizure disorder talked about in an open and sensitive way helps to alleviate some of the fear of what others might think and may help the child to feel less "different." It is important to help everyone in the child's environment to recognize that the child with epilepsy is just like everyone else, with unique qualities and the ability to contribute to and be a valuable part of the community.

Individuals affected by epilepsy and their families have expressed a great need to have information about the disorder and about medical facilities specializing in epilepsy, and to have contact with other families affected by epilepsy. The Epilepsy Foundation of America has a national toll-free information and referral line which can provide families with a wealth of information. This toll-free service, 1-800-EFA-1000, can provide information about affiliates of the Foundation which may serve the area, or support groups located in the vicinity. Medical facilities in towns and cities as close as possible to the family can be identified. Information about epilepsy and its effects can be provided to the family, the child, or to school personnel. A variety of videotapes and brochures are available through the Foundation's Catalog Sales Department to help teach students and faculty about seizure disorders. An educational program called "Count Me In!" is available especially for use by school nurses, and can be shared by several school nurses in one county or state. These are some of the resources available to rural families, and educators can play a role in helping to connect families to these resources. Naturally, one of the greatest resources the child with epilepsy and his or her family can have is the faculty at the child's school. Educators and administrators who are informed about what issues the family may be facing and how epilepsy may be impacting a child can provide the understanding, support, willingness to help, and intervention in the school which children and families say make all the difference in the world.